Next Meeting – Monday, February 5, 2007 – 2 PM Appoquinimink State Service Center Middletown, Delaware

STATE COUNCIL FOR PERSONS WITH DISABILITIES BRAIN INJURY COMMITTEE January 8, 2007 – 2:00 PM APPOQUINIMINK STATE SERVICE CENTER MIDDLETOWN, DELAWARE

PRESENT: John Goodier, Chair; Brian Hartman, Co-Chair; Jim Burcham, BIAD; Dr. Jane Crowley, A.I. DuPont Hospital; Adam Fisher, DOE; Linda Heller, DSAAPD; Tony Horstman, SCPD; Dr. Dan Keating, Bancroft Neurohealth; Lora Lewis, DPH; Chris Long, DDDS; Mike Merrill, VR/U.S. DVA; Tom Parvis, DVR; Ann Phillips, Parent; Al Rose, DDC; Wendy Strauss, GACEC; Liz Schantz, Consumer; Kyle Hodges, Staff and Linda Bates, Support Staff

ABSENT: Dianne Bingham, DPC; Ray Brouillette, Easter Seals; Dr. Jackie Christman, DPH; Virginia Corrigan, Christiana Care; Aaron Deede, Consumer; Janet Leitch, Consumer; Beth Mineo Mollica, DATI; Beverly Stapleford, CDC and Dawn Stewart, Healthy Living

GUESTS:

Devon Dorman, BIAD

CALL TO ORDER

The meeting was called to order at 2:15 PM.

APPROVAL OF MINUTES

Motion was made, seconded and approved to accept the November 6, 2006 meeting minutes as submitted.

AGENDA ADDITIONS/DELETIONS

• Linda Heller will be addressing the Fall Prevention Task Force, and DATI recycling

BUSINESS

Grant Update and Year 2 Deliverables

Lora Lewis from the Division of Public Health gave the following update:

- The deadline for submitting the Year 2 grant application is 1/26 and it is a continuation of Year 1.
- A definition of increase in TBI "awareness" is needed. The evaluation consultant
 has been hired—Gina Perez. The timeline is to complete it is by the end of
 March.
- Brian said that Jim Lafferty from the Mental Health Association had a grant for "awareness" of mental illness and he would be a good contact.
- The second objective is to increase knowledge of prevention and treatment and to continue what has been done in Year 1. Year 2 will be used for distribution of informational packages.
- Another objective is to increase knowledge of TBI support among healthcare providers.
- The resource directory from the BIAD will be refined for distribution. John stated that they are thinking of putting this on a disc and their website and putting a contact for the directory on a tri-fold flyer. It was suggested that the DDC may have a funding if needed. John said maybe a corporation or hospital may have funding available.
- There is an objective to enhance and/or coordinate a surveillance capacity, including development of a traumatic brain injury registry. If you have a registry, you can go back and call the people on the registry to see how satisfied they were with their services. A consultant will be hired to work with the BIC to review the recommendations of the needs assessments by June 30.
- The next objective is to increase professional knowledge of TBI. We will continue to educate surveyors and family health care providers and conduct training of the work force for next year. A plan needs to be developed for the training of the families and the health care providers. This year there will be the conference on educational training. The consultant will be helping the BIC to work on this objective.
- The next objective is to determine legislative and regulatory policy changes needed to enhance TBI supports. A status of these regulatory policy changes will come from Brian and the Policy and Law Committee work. We need to determine the resources needed to maintain and enhance the TBI system. It will have to be figured out how to sustain the TBI effort once the grant is no longer available. This should have started in Year 1 but continues into Year 2. The consultant will also help on this objective. This may be an agenda item in March.

Year 2 (BIC Tasks)

- Address how Delaware is going to implement a surveillance registry.
- How is Delaware are going to apply TBI services to children?
- How is Delaware going to educate survivors and their families?
- How is Delaware going to sustain TBI services and supports after the grant expires?
- A consultant will be hired (part-time) to start on April 1. Linda Heller will e-mail a name of a possible consultant to Lora.

- Kyle asked Chris Long when is DDDS going to give comment on eligibility criteria for children with TBI? Chris will contact Joe and get back to Kyle. Kyle asked for the BIC to review any MOU done between the divisions for eligibility criteria
- Brian said the Division of Child Mental Health has agreed that children with TBI can be served by their division if they meet their eligibility criteria.
- Lora suggested that the consultant come to a BIC meeting. Lora stated that she does not have the budget fully completed. The BIAD will receive \$49,980. The contract evaluation cost is \$15,000. \$20,000 has been set aside for a proposal with Jane and AI DuPont. Jane stated that this money will help establish family mentors (two families in each County) trained on specific information about TBI as well what resources are available in Delaware. In addition, the project will recruit those families for great involvement in the BIAD. The families would be at least one year post injury and showed some capacity to manage their child's situation. Five two-hour sessions of training that would encompass general advocacy, state resources and insurance issues, educational placement, general recovery and medical information. Also, they could be special advisees to BIAD about pediatric issues and how to secure materials. It would be beneficial to have a contact person in all the hospitals on available TBI services and supports. We need to reach out to service providers talking from the family prospective about their experience with the service delivery system (e.g. Easter Seals, some of the Mental Health Services, Delaware Guidance, some of the school's Wellness centers). The idea is that families are going to be paid for their time spent in education and outreach with the assumption that, for six hours a month, they would be dealing with Hotline requests. John said that the BIAD only has parttime staff so if a call comes in Friday evening, it would not be addressed until Monday morning. Kyle said that legislation is being worked on for a 211 line so maybe something could be tied in with that initiative if it passes. Lora said that most federal programs have a response time of 48 hours. Linda added that the State has a 24-hour emergency Mental Health hotline that maybe BIAD could include on their voice message.
- Lora added that there is \$3,600 for the Coordinating Council for Children with Disabilities to support the participation of families (not necessarily those who have a family member with TBI) to come to the BIAD meetings or any other meetings or activities related to TBI in the State. Kyle feels that it would be better to spend the money elsewhere. Linda stated that the Feds are very supportive of any State effort to get consumers involved in committees such as the BIAD or any other committee that would have a significant impact on public policies and programs. There was much discussion on how to get more people to attend the BIAD meetings. Dan said that it seems that we are trying to create a solution before we know what the problem is. Dan suggested trying to determine what families get out of these meetings or what they are looking for before recruiting them for meetings. We need to inform them that that we do not necessarily meet the immediate needs of families and advise them what sources are available. BIC works on systemic issues. Kyle recommended that any families solicited be affiliated with in some way brain injury. Brian said that he

does not want to give the money to an individual in the Coordinating Council as they do not have the background in TBI. Devon Dorman, a guest and member of the BIAD, stated that she was not made aware of all the resources. Dan said that if you want to have family participation, the families would be the best resource to contact. Brian suggested contracting with the DDC. It was also suggested that the SCPD be given the money for this purpose. Ann Phillips said that when she first came to a BIC meeting, she decided to stay to see how, as a family member, she can contribute to BIC and the disability community. Ann felt that she has learned a lot of information and made contacts. Indeed, she is still learning. She noted that when she first started attending the meetings she would have welcomed a mentor. Lora stated that she understands the aforementioned recommendations regarding the use of the \$3,600, but is still inclined to provide this to Coordinating Council

• Lora added that there is \$2,500 for training and \$5,500 for the BIAD conference.

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TBI Summit Proposal

Jim Burcham provided updated materials regarding a TBI Summit. Jim announced that this Wednesday night Larry King is going to focus on TBI issues.

Jim gave the following review on the Two Day Summit Retreat on TBI Issues. Get 75 Stakeholders together—VA, National Guard, Reserves, Army, etc. It was noted that the reservists, who come back from active duty, do not go through the VA system. Other stakeholders include DSAAPD, DPH, DSAAMH, Church and Community Bodies; Survivors/advocates; Treatment programs, Government, Medical professionals; Television; Radio; Internet; Newspaper; Police; Emergency Medical Teams (EMT, Trauma, Neurology); Police and Fire departments.

Funding is needed to pay for two nights lodging during the week. It could be a "retreat" mode, at the Virden Center. Orientation would be on the first night with introduction of work groups and facilitators. The Summit agenda would be provided with some plans for the next 2 days.

Another process would be to select people from various venues and put them into various workgroups. The Work Group Charge would be to: Identify key elements required to develop comprehensive, readable information for the network associated with this to raise public awareness of TBI consequences, treatment options, and resources for survivors their families/advocates/caregivers/service providers.

Kyle agreed with Dan that you need to identify the overall purpose before you can go further. Jane was thinking about a shorter term conference. Jane felt that we should try and have an education of providers and maybe have a day long conference in each County oriented to specific resources in their County. Dan feels that you need to address the needs of the first responders by pulling a group together to do this. Ann said that we cannot put truly plan a conference until we see the results of the needs assessment. Dan

commented that you need to find out from surrounding states things that you do not have in Delaware—some providers may not know what is not being provided. Lora added that the families will be surveyed in Year 2. Ann has to have her assessment reports done by March 31. Kyle suggested narrowing this conference to a one day—and then expand as needed. Lora added that one of the deliverables for the BIC in year two is that it needs to develop an educational plan relating to the needs assessment in year one. Kyle suggested that we revisit issue this after March 31 with a small group and the consultant. The committee appreciated the work by Jim on this issue, but cannot commit to a specific type of conference until the results of the needs assessment are determined.

PATI Report

I. FY 06 PATBI Annual Report

The DLP submitted its FY 06 annual report (covering October 1, 2005 through September 30, 2006) to the NDRN on December 7, 2006. A copy of the 31-page report is attached. The report highlights the collaborative work of the SCPD Brain Injury Committee.

Brian added that this is a \$50,000 grant.

II. HRSA Grantee Meeting

Brian will be attending a HRSA-sponsored PATBI grantee meeting on January 10 in San Diego. The meeting is expected to focus of the following: 1) veterans outreach; 2) cultural competence; and 3) proposed reporting format. I expect to report on the results of the meeting at the Committee's February 5, 2007 meeting.

Brian added that he will be bringing VA information for Mike.

III. DOE Unit Count

The GACEC obtained the results of the latest (September 30, 2006) Department of Education unit count. The number of students classified under the TBI category has increased to 30 statewide. The following districts reported zero (0) students with TBI: Appoquinimink, Caesar Rodney, Capital, Laurel, Milford, NCC VoTech, Smyrna, and Woodbridge. The DOE otherwise shared its inability to provide a breakdown of numbers by district.

Adam will get the TBI breakdown by district in January—the number may go up as well.

IV. LIFE Conference

Registration for the LIFE Conference IX is still open. On-line registration is available at www.lifeconference-de.org. The conference will convene at the Dover Sheraton on January 25, 2007. A copy of the "Agenda at a Glance" is attached.

Kyle provided Life Conference registration forms. Jim added that the BIAD will be an exhibitor.

V. National Geographic Article on Iraq Veterans with TBI

Brian provided an article on Iraq veterans which appeared in the December issue of National Geographic. Ninety percent (90%) of the patients with TBI treated at Walter Reed had "non-penetrating head injuries - concussive wounds that may not be immediately apparent". Sixty percent (60%) of patients with TBI treated at Walter Reed had moderate to severe TBI. Apart from statistics, the article describes in detail one soldier's experiences upon returning from Iraq and his slow recovery.

VI. Flexible "Hard Hats"

An article from the December issue of Popular Science describes a new development which could reduce the incidence of TBI. Knit caps are manufactured with elastic polymers which harden in microseconds upon impact to absorb and redistribute the force of a crash. It is used in caps for skiing and other sports.

VII. NCC In-Law Suite Ordinance

Accessory apartments (a/k/a in-law suites) provide an option for persons with TBI who would prefer a low-cost, independent residence but benefit from the availability of nearby family support. Unfortunately, zoning codes serve as a barrier to development of such apartments. Based on an August 19, 2006 News Journal article, the SCPD issued the attached September 8, 2006 letter endorsing the concept of an ordinance authorizing accessory units. A December 24, 2006 News Journal article mentions AARP and SCPD support and anticipates introduction of an ordinance on January 12, 2007.

Brian would encourage other organizations to endorse the ordinance. The article notes that some civic organizations may oppose it based on perceived protection of property values and single family neighborhoods.

Kyle added that an introduction and reading will be held tomorrow on January 9, 2007. A citizen's planning board meeting to receive public comment will be on February 6th at the City/ County Building—Kyle can get the time if anyone is interested. March 13 is the proposed date for a final vote. Brian encouraged organizations to endorse this ordinance. It was agreed to defer this to the Policy and Law Committee. However, once a letter is written, it could be e-mailed to members of this committee and other organizations for their follow-up for endorsement.

VIII. Tort Reform

TBI survivors who are the victims of negligence (e.g. auto accident; business slip and fall) often rely on claims against the perpetrator to recover damages. A January 8, 2007 Business Week article describes the national movement towards restriction of damage awards. This has an adverse impact on the ability of TBI survivors to receive fair compensation for injuries. "Tort reform" is a "live" issue in Delaware and the Committee may wish to become involved if restrictive legislation is introduced in 2007.

IX. Worker's Compensation

Employees who experience a work-related TBI must generally rely on Worker's Compensation for both resulting medical and lost-wage claims. It is therefore an important "safety net" program for work-related TBI survivors. Consistent with a July 2, 2006 article, a 74-page bill was introduced last June to totally revamp the Worker's Compensation system. The impetus is high insurance premiums. The bill was not employee-oriented and the DLP submitted a lengthy critique in June.

New legislation is now expected to be introduced in January, 2007. There is tremendous pressure from business interests to pass an employer-oriented bill.

Bobby Byrd, a long-time lobbyist, is quoted in another January Delaware Today article as predicting quick passage of a Worker's Compensation bill in January, 2007. Moreover, a January 5, 2007 News Journal article quotes Lt. Gov. John Carney as characterizing "Workers' Compensation" as "a January issue". Advocates will have to be vigilant to have any impact on the bill.

Brian added that Delaware has the third highest worker compensation rates and only Alaska and California have higher worker compensation rates. Supposedly, because the system has not been upgraded in years. A new bill will have to be enacted on quickly this month.

Brian added that an article in the News Journal was provided on bicycle riders on Rt 1 at the beach. Secretary Wicks is going to hand out free helmets and educational materials. Kyle agreed to encourage Ginny Corrigan to send TBI information to DelDOT. Motion was made, seconded and approved to send Secretary Wicks a letter of support for this initiative.

OTHER BUSINESS

- Linda Heller announced that the Injury Prevention Coalition has just formed a Fall Prevention Task Force Committee to help implement the goals within the Strategic Plan for TBI and Spinal Cord Injury Prevention plan for children and adults. Linda welcomes the BIC input and will keep everyone informed of the Committee's progress.
- Linda also announced that the Delaware Recycling AT grant of \$600,000 (Dr. Beth Mineo-Mollica) had a two-day kick-off retreat. Linda will send Kyle a copy of the meeting schedule. Linda welcomes the BIC input. Liz felt that this was

ANNOUNCEMENTS

- John Goodier announced that the BIAD conference will be held on Wednesday, October 24 at the Dover Sheraton. The topic will be "The Road Back". Dr. John White and Neil Kaye will be the speakers with Cole Gallaway as the moderator for the panel on brain injury survivors that have survived on various levels. Ginny Corrigan has agreed to provide the CEUs. The flyers will be sent out in April or May.
- John will send a copy of the BIAD minutes to the Advisory Board so they know what is going on in the organization. March is Brain Injury month with a proclamation at a luncheon with the Governor. This year's advocacy award will be going to Brian Hartman.

The next meeting will be held on February 5 at 2 pm at the Appoquinimink State Service Center in Middletown.

ADJOURNMENT

The meeting was adjourned at 4:15 PM.

Respectively submitted,

Kyle Hodges SCPD Administrator